## AUGUST 2015 Volume 29, Issue 3

Newsletter of the American Parkinson Disease Association Greater St. Louis Chapter

Serving Missouri and Southern Illinois

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American Parkinson Disease Association

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#### **OUR MISSION**

Our mission is to enhance the quality of life for people with Parkinson disease, their families, and caregivers in our communities throughout Missouri and southern Illinois, and to provide funding for ongoing Parkinson research.

# **The Helplessness Antidote**

Peter Dunlap-Shohl

Peter Dunlap-Shohl has worked as cartoonist for the Anchorage Daily News for over 25 years. He was diagnosed with Parkinson disease in 2002 and maintains a blog about living with Parkinson's that features original cartoons and illustrations.

here was no reason I deserved a visit from an angel. I didn't believe in them at the time, nor do I now. Nevertheless, as I walked from my doctor's office in a haze of questions, fears, and old-fashioned misery, it was waiting for me. Waiting because a simple sentence had just laid

waste to my plans, my dreams, my 43-year old life, "I think you have Parkinson Disease."

How could I have Parkinson's? How long could I simulate "normal"? When would I have to give up my job? What would this mean for my family? When should I tell my friends? The questions were silenced by a voice that rang with clarity and conviction. "You have to exercise!" the angel's voice intoned, "or you will descend in no time in an ever-steepening spiral to complete incapacity." The angel left me, in effect,

with a little stone tablet bearing the 11th Commandment: "Move it or lose it." It was a moment I think of as "The Visitation of the Spandex Angel."

Where the angel got its information, I don't know. This was over a decade ago, and though I burned up the Web in a search for something, anything, that could give me a straw to grasp, there was little there. Dr. Jay Alberts had yet to publish his signal discovery concerning tandem bicycling and the substantial symptomatic relief it can bring. There was no mention of the role Yoga, Tai-Chi and dance can play in aiding the crucial ability to balance, keeping us, PD patients, out of hospitals with broken bones. There was nothing about the value of boxing, or weight-training, or the bigmovement strategy that now constantly make news in the Parkinson's community.



I had nothing to go on beyond the urgent proclamation of my mystic visitor and the conviction that, with my body under assault by this mysterious and destructive disease, I had to do all I could to protect the underlying strength and ability to move that I still possessed. So it was a matter of faith for me to get out of bed each morning, climb on my elliptical trainer and go as fast and hard as I could for a half-hour, five times a week. But it wasn't long before it was clear to me that I was seeing mitigation of my symptoms. My

tremor visibly subsided after a good exercise session, and my speech improved. While out riding my bike, I would catch myself not only singing, but actually hitting the notes I was aiming for. And nothing dissipates the fog that rolls thick around my head in the mornings more effectively than exercise. These effects and the research that shows they are no mere fluke should be familiar gospel to anyone coping with PD.

But here are two additional reasons to move your body. The first, beyond the benefits cited above is, it just feels good.

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Disclaimer: The information and reference material contained herein concerning research being done in the field of Parkinson disease and answers to readers' questions are solely for the information of the reader. It should not be used for treatment purposes, rather for discussion with the patient's own physician.

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disease forces you into a wheelchair, you will at least have made the most of your ability to move while you could and probably made that window in time when movement was possible larger than it would have otherwise been. Second, until these recent discoveries about exercise, all we could do was manage our decline. We were told our disease was

Should the day come, at last, when Parkinson

The Helplessness Antidote continued from front page

progressive, incurable, and disabling, and we were helpless to do anything to change it. Helpless. Exercise can liberate us from this deadly feeling, freeing our spirits as we free our bodies.

This article appeared in the NWPF publication on April 24, 2015, and is reprinted with permission of NWPF. Peter is a blogger in this wonderful weekly publication.

## **Managing Constipation in Parkinson Disease**

Kathrynne Holden, MS, RD, is a Registered Dietitian specializing in PD. She has authored many books about PD, including *Eat Well, Stay Well With Parkinson's Disease* and *Nutrition Matters.* 

Constipation is among the most common non-motor symptoms of Parkinson disease. It can occur years before diagnosis in some people. This happens when PD affects the autonomic nervous system that guides the movement of the muscles of our gastrointestinal tract, including the colon. The movement, called peristalsis, becomes slowed so that the stool moves more slowly through the colon.

The task of the colon is to receive watery indigestible residue from the small intestine and then, as the residue moves along, to remove some of the water. Gradually, as it travels through the colon, the residue becomes a soft, bulky stool that is easily passed. But when we don't consume enough liquids or fiber, the residue is not as watery. The colon continues removing water, but the stool moves slowly. Too much water is removed, leaving a hard, dry stool that is difficult to pass. This is what we know as constipation.

Prolonged constipation can, in some people, affect medications. PD medications may fail to take effect. Then, when a bowel movement does occur, the medications can "kick in" within minutes. But until then, the person may experience prolonged "off time."

How can constipation be prevented? When peristalsis is slowed, it becomes more important than ever to pay careful attention to daily meals. Highly-processed foods, made with refined flour and sugar, have been stripped not only of their natural minerals and vitamins, but of their fiber also. Avoid these highly processed foods. Instead, choose whole-grain breads, crackers, and breakfast cereals. Use honey, maple syrup or stevia for sweeteners rather than foods made with sugar and high-fructose corn syrup.

**High-fiber foods** Next, look for foods that are naturally high in fiber. Most vegetables and fruits contain a variety of fibers and pectins, all of which are important to our health. Raspberries, pears, and apples are among the highest-fiber fruits, while artichokes, green peas, broccoli, leafy greens, such as turnip greens and spinach, and sweet potatoes are high-fiber vegetables. Soluble fibers help control blood glucose; insoluble fibers keep the stool soft and bulky. Both may act as a substrate ("food") for friendly bacteria in the colon.

Whole grains contain complex carbohydrates as well as fiber, and can be a valuable addition to the menu. Whole rye and whole wheat bread, oatmeal porridge, brown rice, and barley (preferably unhulled barley which is one of the highest-fiber grains) are excellent everyday foods.

Legumes (dried beans, peas, and lentils), seeds, and nuts are also extremely high in fiber as well as important sources of minerals, such as magnesium, and vitamins, such as folate. Legumes should be included in meals at least three or four times a week. Split pea soup, hummus, Cuban black beans, bean salads, casseroles, and refried beans are just a tiny fraction of the multiple ways to use and eat beans. If you have a pressure cooker, you can cook them yourself and control the salt and flavoring, but canned beans are inexpensive and perfectly good as well. Chia seeds, flaxseeds, sesame seeds, coconut, almonds, and sunflower seeds are all rich in both fiber and healthful fats.

continued on page 12

# **Mindfulness Works in Parkinson's Patients**

John Zapanta, PT, DPT, conducts research, and McKay Murdock, SPT, is a physical therapist intern at the Colorado Physical Therapy Specialists.

Past research has already shown that exercise can significantly reduce symptoms of PD and help a person move and feel better. However, the World Health Organization defines health as "a state of dynamic harmony between the body, mind and spirit of a person." So is there more that we can do besides just exercise to counteract the effects of PD? Researchers respond with a resounding "yes!"

Enter mindfulness. Those who practice mindfulness have been shown to have enhanced immune systems, relief from chronic illnesses, decreased anxiety, better focus, increased satisfaction with exercise and even structural brain change, a process called neuroplasticity.

So what exactly is mindfulness? The exercise of mindfulness can include breathing, self-talk, visualization or more advanced methods such as tai chi and qi gong. By practicing mindfulness along with a physical fitness program, one may engage the whole body and mind to improve neuroplasticity.

# Research on the benefits of mindfulness for neurologic diseases such as PD has exploded.

Long-term mindfulness practitioners increase the working capacity of the brain, connections within the brain and brain matter compared to non-practitioners. This suggests mindfulness may keep brains young and healthy. An eight-week mindfulness training program makes measurable changes in the brain structures associated with learning and memory, sense of self, empathy and stress. Only four days of mindfulness training can enhance the ability to sustain focused attention. It also shows significant improvements in mood, visuo-spatial processing, working memory, and cognition.

Dr. Norman Doidge, MD, a leading expert in neuroscience and medicine, has made some fascinating discoveries on the power of the mind, as described in his book, *The Brain's Way of Healing:*  Remarkable Discoveries and Recoveries from the Frontiers of Neuroplasticity. Dr. Doidge recounts the story of how his friend with Parkinson's was able to normalize his walking pattern. He did this by slowing down his walking, using extreme "meditative" concentration to break apart each step, and practicing for a full year. He found that by bringing the movement into conscious attention, he was able to take advantage of different brain areas that were not affected by PD.

This same friend eliminated his tremors by being more aware of his movement. For example, he held his glass of water more firmly, fixed his handwriting by switching from cursive writing to printing capitals, and discovered that by holding his fork at 45 degrees toward himself that his tremor disappeared. Other brain stimulation activities he used included crosswords, Sudoku, bridge, chess, poker, dominoes, recording CDs of himself singing, and learning French.

A longtime practitioner of mindfulness for 10 years, Rob Piper, a Fort Collins, Colorado, resident, was diagnosed with PD in 2014. He describes mindfulness in his life to be "living in the present moment and not dwelling in the past or future." Mindfulness has helped him acknowledge his thoughts and emotions by being more present and responding to them rather than reacting to them. Sometimes he feels anxious regarding the future of his PD, but he is able to use mindfulness training to calm his anxieties and have more control of his mind and body. He describes how breathing is a "natural tranquilizer" that makes him feel more focused during the day, improves his sleep at night, and makes him more consciously aware of his physical movements.

He describes being more conscious of all of his senses during exercise. He sees more clearly, feels the hiking poles in his hands and the rocks underneath his shoes, smells the fresh air, and hears nature around him. Rob considers mindfulness to be an integral and positive experience for both his physical and nonphysical symptoms of Parkinson's and recommends it to those who are interested in practicing it.

# **Excessive Daytime Sleepiness in Parkinson Disease**

Baijayanta Maiti, MD, PhD, Clinical Fellow, Movement Disorders Section, Department of Neurology, Washington University in St. Louis

Although the key motor symptoms of shaking, stiffness, paucity of movements and balance problems have traditionally received more attention and are quintessential features for the clinical diagnosis of Parkinson disease (PD), a mélange of non-motor symptoms including fatigue, anxiety, excessive daytime sleepiness (EDS), depression, pain, constipation, and bladder problems can often be more troublesome to the patient and at times can even precede the onset of motor symptoms.

DS is one of the more common nonmotor symptoms and greatly impacts the quality of life of PD patients, often by imposing another set of restrictions on their activities. The prevalence of EDS in PD patients has been reported to be anywhere between 15-75%. EDS has gained wide attention ever since the initial report in 1999 of sleep attacks in eight PD patients, all of whom suddenly fell asleep while driving. Incidentally, they

were all taking dopamine agonists, a class of antiparkinsonian medication. Although a few studies have suggested a stronger association of EDS with these agonists than levodopa (another widely used antiparkinsonian medication), other groups have found it is the total amount of dopamine supplementation and not the specific category of drug that matters. Concurrent use of medications with sedative side effects could also worsen EDS, but EDS is not merely

a treatment side effect. Few studies suggested that it could be a manifestation of PD itself and could worsen with disease progression; however, other studies have failed to prove this association. Several studies have also implicated multiple sleep problems to be contributing to EDS. These include:

- Sleep fragmentation (multiple nocturnal awakenings either due to wearing off of levodopa resulting in stiffness or even emergence of shaking, or nocturia i.e., waking up multiple times in the middle of the night to go to the bathroom)
- Sleep apnea (multiple transient episodes of involuntary cessation of breathing during sleep)
- REM sleep behavior disorder (RBD, marked by dream enactment)

• Restless leg syndrome (RLS, where there is an irresistible urge to move the legs due to an underlying unpleasant sensation, occurs usually during rest at night, and resolves with movement)

The association of EDS with depression is somewhat less clear. The discordance in the published literature regarding the potential contributory role of each of these factors could be attributed to the varying characteristics of the investigated pop-



ulation in terms of disease severity and duration, accompanying cognitive impairment, or due to inferences drawn from an inadequate number of study subjects and varying scales used to assess EDS in these studies.

EDS is usually assessed in the clinic by a brief, standardized, widely used self-questionnaire called the Epworth Sleepiness Scale (ESS), which is a subjective measure of the propensity to fall asleep in certain daily life situations. A score greater than 10 is usually considered pathological. A more objective way to measure EDS is using MSLT (Multiple Sleep Latency Test), which is a measure of one's ability to fall asleep during daytime in standardized test conditions. A recently conducted large scale study by a French group used both subjective and objective measures to evaluate the role of potential contributory factors. This group found only a weak correlation between these measures. While

about 46% of enrolled subjects had subjective sleepiness, only 13% fulfilled the criteria for objective sleepiness based on the MSLT. Interestingly, PD patients with sleepiness had higher BMI and were more frequently overweight than those without EDS. Pain and sleep apnea syndrome also proved to be key contributory factors of EDS in this study.

If you develop excessive daytime somnolence, you should discuss it with your

doctor. While there is insufficient evidence for pharmacologic treatment of EDS, stimulants like modafinil and caffeine have shown some benefit in small trials and could well be an option in carefully selected cases. However, there are other measures that could potentially improve EDS. Eliminating drugs with sedative side effects, whenever feasible, or optimizing the medication regimen often makes a significant difference. Pain can often

be a sensory manifestation of PD itself or could be secondary to off-period dystonia, both of which could respond to levodopa dose adjustments. If there is a definitive temporal relationship of EDS with antiparkinsonian medication, minor dose adjustments or switching the drug class could be effective. Appropriately evaluating for and addressing comorbid sleep problems like sleep apnea, treating RBD with clonazepam, an extra dose of levodopa at bedtime to prevent nocturnal wearing off, or even simple measures like avoiding extra fluid intake after dinner to prevent nocturia could ultimately improve quality of sleep and potentially ameliorate EDS. Lastly, the merits of regular exercise cannot be overemphasized. It helps regularize the sleep wake cycle, prevent insomnia, manage body weight, and could thus have a significant positive effect on EDS in addition to its proven long-term global health benefits.

# **Sing Your Way to a Better Voice!**

Linda McNair, MT-BC, is Music Director of Tremble Clefs of Greater St. Louis and a Music Therapist at Bethesda Meadow in Ellisville.

About 90% of people with Parkinson's will experience changes in their voices or their ability to make speech sounds during the course of the disease. These changes may make a person's speech less precise and more difficult to understand. Most commonly, the voice becomes quieter. Other symptoms include a narrowing of the vocal range resulting in monotone speech, difficulty sustaining breath while speaking, and/or a breathy or hoarse quality. The symptoms can lead to difficulty in communicating with family and friends as well as frustration on the part of the individual living with Parkinson's. In spite of all the changes occurring, one can affect a change and positively make a difference. There are a number of therapeutic interventions that research has shown can maintain and even improve one's voice.

One of the therapeutic interventions receiving increased attention is singing. In an exciting new research study conducted at Iowa State University, Dr. Elizabeth Stegemoller, Ph.D, MT-BC, examined the effects of structured singing on individuals with Parkinson's. Prior to beginning her study, Dr. Stegemoller screened her participants to determine voice quality and swallowing ability. Additionally, each participant completed a quality of life survey. Over the course of eight weeks, individual groups



met at four different study sights across Iowa. Several of the groups met twice weekly while others met only once a week. Each of the groups followed the same format for their rehearsals and was led by a music therapist.

The sessions began with a "hello song," after which the participants proceeded through a series of vocal exercises that focused on improving the muscles used in singing as well as swallowing. Once the warm-ups and exercises were completed, the groups sang a selection of familiar songs. A closing song completed each session. At the conclusion of the eight-week study, Dr. Stegemoller again assessed the participants for voice quality, swallowing, and quality of life. The results demonstrated a significant improvement in the areas of vocal volume, the ability to breathe in and out more efficiently, swallowing, and overall positive changes in quality of life. Her research gives strong support for the use of group singing when led by a certified music therapist.

According to Dr. Colum MacKinnon, PhD., Assistant Professor in Neurology at the University of Minnesota, "Data shows us that listening to music increases dopamine." Michael S. Okun, M.D., University of Florida Health and Professor of Neurology, seems to agree with this statement, adding that "there is mounting evidence to support the idea that singing can benefit Parkinson disease patients, and Dr. Stegemoller's study shows that benefits extend beyond just the voice, which is interesting and may have practical implications for the field."

Any work towards strengthening the voice is vital to maintaining the ability to communicate and keeping the voice healthy. With the current research showing evidence of

significant improvements in four distinct areas (voice volume, breathing, swallowing, and quality of life), why not consider joining a vocal group such as the Tremble Clefs? Tremble Clefs of Greater St. Louis meets each Saturday in Ladue from 1:30-3:00 p.m., and rehearsals follow much the same format as was outlined by Dr. Stegemoller.

Tremble Clefs of Greater St. Louis is in the process of conducting its own research. Under the guidance of Erin Foster, OTD, MSCI, OTR/L,

Assistant Professor of Occupational Therapy, Neurology and Psychiatry at Washington University School of Medicine, Sarah Risso is currently conducting research with our Tremble Clefs group. Hoping to lend even more support to group singing, Sarah, MSOT/S, is directing the research as she completes work on her master's degree in Occupational Therapy.

Dr. Stegemoller suggests the best way to incorporate music into your life is to listen to music, but not just any music – listen to your favorite preferred songs. "Sing in the car, sing in the shower. It doesn't matter. Take time out of your day to sing whatever you want. It will help your mood and will work the muscles that affect swallowing and speech." The Tremble Clefs group is always open to new members. If you or someone you know would like to consider joining the group, please call the APDA office 314-362-3299 for more information. Come, be part of the fun and sing your way to a better voice! ■



# Putting for Success – Another Perfect Round!

his year's 17th Annual APDA Golf Classic in memory of Jack Buck, held on May 18, 2015, was our most successful fundraiser ever, raising just over \$138,000 for patient services and Parkinson research.

The event, with the generous assistance of Honorary Chair John Mozeliak and Auctioneer & Emcee Tom Ackerman, also served to increase the awareness of Parkinson's in our local community. It was another great day for golfing at Algonquin Golf Club in Glendale!

Our success was attributed to our loyal sponsors: **CELEBRITY** level sponsor: Moneta Group; **MAJOR** level sponsors: Selequity, Sterling Bank, Teva Pharmaceuticals and Wells Fargo; **GOLF CART** sponsors: Carol House Furniture and KPMG; **CONTEST** sponsors: Benton Homebuilders Community Partnership, BJC HealthCare, Enterprise Bank & Trust, Express

Scripts and Riverside Furniture; LUNCH sponsors: Scottrade and Dave & Suzie Spence; COCKTAIL RECEPTION sponsors: Budget Billboards, Inc./ For Pete's Sake, Delta Dental. Steve & Lynn Hurster, Merrill Lynch Wealth Management and the St. Louis **BEVERAGE**/ Cardinals; **SNACK** sponsors: John & Jean Basilico, Centric Group, Gershman Commercial Real Estate, SE Farris Law firm; DRIVING RANGE sponsor: DTZ; and HOLE sponsors: Ameren, Argent Capital



Bob Gibson autographing Kyle Lucks' painting

Management, Don Carlson, Cooperative Home Care, Larry and Sonya Davis, The Delmar Gardens Family, Express Scripts, Fastsigns of Bridgeton, Keith & Cindi Guller, Henges Interiors, Horner Shifrin, Husch Blackwell, Kodner Gallery, Missouri Cures Education Foundation, Petro-Mart/Western Oil, Inc., Reitz & Jens, Inc., Shillington Box Company, Serta Mattress Company. Our **EXCLUSIVE RADIO PARTNER** KMOX allowed us to market and promote the golf tournament, which also helped raise awareness of the APDA and Parkinson disease.

**CHARITABLE CONTRIBUTIONS** arrived in generous proportions from Jeff Fox, Larry and Gail Glenn, Suzanne Hurster Wood, Tom and Amy Mackowiak, George and Nancy Marble, Morgan Stanley, PJG and Associates, Marty Satz, Al and Alice Schott, Bob and Jennifer Schuller, Jack Strosnider, Marilyn and Bob Warren, George "Butch" Welsch, Bob and Lynda Wiens.

**AUCTION ITEMS** were donated by Tom Ackerman, Asymmetric Solutions, Autohaus BMW, Golf Discount of St. Louis, Gary Hoemann, Kyle Lucks, Mister Guy Clothiers, Dan McLaughlin, John Mozeliak and the St. Louis Cardinals.

Caps off to these special **VENDORS** who helped make the event a success: Autohaus BMW for the hole-in-one car;



Tom Ackerman



Gil Hoskins, Bob Warren, John Mozeliak, Bill Warren, Bobby Warren

Crown Trophy for the crystal golf awards (in loving memory of Max April, Shale M. Rifkin, and Ben April); Fastsigns of Bridgeton (Barry Roufa) for the wonderful signage and pin flags; Zach Dalin and Bryan Schraier for their professional photography services; Pretzel Boy's and the St. Louis Cardinals for hot pretzels and beverages on the course; and Tom Ackerman, Dan McLaughlin & John Mozeliak for media/marketing leading up to the sold-out event.



Doug Schroeder



John Mozeliak

Doug Schroeder, a Boeing engineer diagnosed with early onset Parkinson's, spoke to the crowd about optimism and PD. Dr. Perlmutter, the Medical Director of the Greater St. Louis APDA, Head of the Movement Disorders Section and a distinguished Movement Disorder Specialist at Washington University, shared with our golfers and dinner guests the hopefulness he feels as a scientist working to find causes and a cure for this disease.

He also expressed his gratitude for

Bob Warren, Bill Warren, Grant Washburn, Jim Whitledge, Jeff Wist and Marty Zygmund.

We can't forget to thank our 136 golfers who had a great day on the greens, bidding on many wonderful auction items, enjoying the Question-and-Answer session with John Mozeliak and Tom Ackerman, and feasting on the dinner served by wait staff at Algonquin. Auctioneer-extraordinaire Tom Ackerman secured bids for our one-of-a-kind live auction items including a unique, signed painting of St. Louis Cardinals Hall of Famer Bob Gibson by Kyle D. Lucks; the opportunity to throw out the first pitch, dine in the Cardinal Club, visit the field and watch a St. Louis Cardinals game with three friends in a field box; a party suite for 30 people at a Cardinals game; a visit to the GM's private box with dinner and drinks, plus four infield box seats; an in-studio visit to Sports Open Line and dinner at Mike Shannon's Steaks and Seafood; four tickets, on-the-field batting practice access and a visit to



Kyle Lucks



Steve Deines, Bud Raskestraw, John Mozeliak, Joel Perlmutter, Mwiza Ushe

the generosity and support provided as a result of this

fundraising event. As a result of Doug's inspiring story and Dr. Perlmutter's speech, almost \$26,000 was collected during the **FUND-A-NEED** portion of the evening from the charitable individuals/couples present: Todd Anstine, Matt Bayer, Kena Blanton, Dave Butler, Rich Chrismer, Jerry Clerc, Ed Dickinson, Laura Dobsch-Mayer, Anne Droese, Chris Edwards, Jim Gidcumb, Ed Goedeker, Patrick Hoene, John Hogan, Gil Hoskins, Kevin Kozminske, Matt LaMartina, Alex Lee, Alan Lemley, Mark McPeek, Jason Morris, Scott Mosby, Dean Mueller, Bob O'Connell, Brian Potter, Tim Potter, Bill Reller, Barry Roufa, Dave Sadler, Matt Schumacher, Rich Schumacher, Ross Schumaker, Rich Smith, Sandy Steppig, Karen Vangyia,



Mike Johnson, Steve Ackerman, Ryan Martin

Schumacher, and committee members Matt LaMartina, Mark Lawson, Alan Lemley, Barry Roufa, Dave Sadler, and Grant Washburn; as well as John Basilico, Kay and Rebecca Bruchhauser, Ann Cook, Andy Dalin, Elaine Dreher, Karl Guyer, Barb Koch, Benjy and Joyce Levin, Craig Miller, Nancy Schillinger, Marilyn Warren and Sherre Wiedemann. A big thank you to our tireless volunteers from Scottrade who spent the day with us as part of their community day of service: Andrew Barco, Matt Black, Mary Ferry, KC Grun, Scott Deters, Andrea Hussey, Sarah Krantz, Krishna Rao, Matt Spector and Mary Lou Sullivan.

Please consider volunteering to join our golf committee, or if you wish to receive an invitation for next year's golf tournament to be held on Monday, May 16, 2016, at Algonquin Golf Club, let us know by phone: 314-362-3299 or e-mail: malmengor@ apdaparkinson.org.

the broadcast booth; opportunity an to hit the links in style with gift cards to Mister Guy Clothiers and Golf Discount, plus a foursome at Algonquin Golf Club; Navy SEAL training for а day; and a BMW Carbon Racer Bike.

It does indeed "take a village" – special recognition to our hard-working **VOLUNTEERS** under the direction of Golf Committee C o - C h a i r s , Matt & Annemarie

# TRIBUTES & DONATIONS 04/01/15-06/30/2015

Tributes are a thoughtful way of expressing sympathy, giving thanks, celebrating special occasions such as birthdays, anniversaries, holidays; or honoring the memory of a loved one or friend while expressing your commitment to the Greater St. Louis Chapter of the American Parkinson Disease Association. An acknowledgement including your name (but not the amount) will be sent to the person honored or to a relative in case of memorial, and the donor will receive a promot thank you card/letter which can be used when filing your tax return.

#### HONORING

## Stephanie Alport on a speedy recovery

Pam & Jerry Brown

John Basilico on his birthday and with appreciation Debbie & Karl Guver

*Mr. & Mrs. Harvey Brown on their 65th anniversary* Rita Eiseman

*Mr. & Mrs. Robert Brown on their special anniversary* Pam & Jerry Brown

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James Crates Lisa Knoll

Dick & Sue George Rochelle Weiss & Steve Lobe

Marilyn & Arnold Goldman on their 40th anniversary Steve & Marilyn Dardick David & Sabina Garfinkel Herbert & Nancy Seidel

Ralph P. Goldsticker, Jr., on receiving the French Legion of Honor Medal Larry & Andi Goldsticker

Debbie Guyer Jean Grifford for her work in the Parkinson community in Ste. Genevieve Jack Strosnider, Sr.

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*Our 49th anniversary* Bill & Susan Stafford

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*Terri & Bill Taylor on their anniversary* Roz Gad

#### Elaine Varnadore on her birthday, in memory of her parents

Sharon K. Holt Beverly Lee Janie Walter on her birthday

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*Shirley Cohen* Joanie & Mark Goldstein

#### William Cornman

Michael & Beverly Compton Thomas Franzen Ronald & Elaine Graiff Becki Hartke Leland & Janis Johns Marty Kalaher Edward & Pamela LaBelle Robin & Linda Meade William & Lisa Montgomery Robert Ostendorf Shirley Rull Peter & Cindy Sevin Martin & Grace Schneider Robert & Linda Speas Greg & Cindy Watters Glen & Esther Watts Andy Westhoff Brett & Laurie Whitnel Bennett & Evanell Williams

#### Barbara Correll

Patti Fries-Koch & Dolores Fries

*Francis Craig* Robert & Lynda Wiens

*William Cribbin* Jack and Peggy Cribbin

*David Deem* Janet Dobbs

#### Frank Deranja

Maria Cendekawitsch Joanne Corcoran Janet Deranja Fatima Kucic Ana Pluchinski Vinka Rukcic Juliana Stefulik Angelika Ziglioli

Ralph Eaves

Clyde & Carol Hayes Kinch & Thelma Joyce Jones James & Sharon Patrick Jeanne Shaw

*Bill Erdman* Christy Hayes

Phil Erzinger Jeanetta Brinkman-St. John's Cancer Relayers Deborah & Curtiss Crosser

*Stanley Fagin* Sharna Kohner

*Rev. Ronald Feuerhahn* Bob & Melissa Mullgardt Robert & Lynda Wiens

Guy Frumson Sally Reinholdt

#### Robert Geile

Sue & Jim Adams Tom & Paula Andrew Jim & Kathleen Baalmann Angela & Brian Bachelier Henry & Ann Bauer Tracy & Cathy Beckette Russell & Mary Bellerson Diane & Joe Bottani Andrea & David Braun Debbie Brooker Helmut Brugman Amy Clements **Rivalie Cohn** Renie & Bill Compton Jim & Diane Daly **Richard & Carolyn Dames** Katherine Deisanti Lauren DeVous

Janet Dobbs Donald & Celeste Dwyer Bob & Gail Einspanier Gerald Erker & MP Gallagher **Billie Farrell Beverly Friedman** Jim & Eileen Fritsch Lou & Carol Garr Russ & Ann George The Gipsons Debra Gordon Karen & Jim Halla **Bill & Linda Hambrick** Mary Rose & George Heil Thomas & Barbara Hilton John Humphrey, III Adrian & Gave Ann Hutton Harry & Laura Ingram Susan Jaggie Janice Kilgen Bill & Mary Kramper Betty Kraner Dennis & Susan Kruep Alex Kusnierkiewicz Brian & Brooke Lunt Jessica & Scott Mangus Elizabeth Mast Susan McCoole Kellv McKittrick Laura Meyer Garry & Genevieve Moeller Anne & Brian Murray Joseph & Peg Niemann Janice A. Noack Burton & Carolyn Noll James & Connie O'Connell Kerry & Joseph Pantelis Mr. & Mrs. Jeffrey Pawlik Katie & Matt Pelikan Jim & Georgia Peterson Mike & Chris Pitzer Jon Phillips **Ruth Powell** Mary McShane Reckamp Deborah Reimer Brooke & Jim Rintoul Mr. & Mrs. Ryan Rothkopf Dave Schwent John & Sigrid Sheehan Chad & Beth Silker Jim & Janet Singer Steve & Amie Smith Mike & Kim Sullivan Carol W. Szweda Nicole Timlin & KECC Family J. Kent Underwood Gary & Donna Vandiver Lea Virtel Clarence & Mary Nina Wagner Mary & Raymond Watts Peter & Teresa Wetzel Carl & Rose Will Ray & Mary Winkeler Loretta & Charles Wittenberg Mary & Terry Wittenberg

*Tony Gerner* Patricia Anghilante Helen Goldsticker Andi & Larry Goldsticker

*Ismael Herrera* Anthony & Kathleen Bommarito

*Marigrace Hoffman* Gloria Hurley

#### Robert Hofmann

Sandra & Jerry Barklage Richard & Lisa Beckmann Alan & Connie Button Defiance & Wright City Quarries Jerry Lee & Billie Jean Diekamp Herb & Lisa Homeyer Russell & Robin Illy Lucille Kasper Glen & Kari Keeven Joanne Keeven Candace & Randy Politte Arlene Rothermich Tim & Barb Schwane

*Joan Hollander* Rita Eiseman

*Marvin Holtzman* Fran & Sid Axelbaum Roz Gad

Richard Karney Carol Faintich Marsha & Steve Funk Minnie Kaplan Sandra Turk & Family

*Robert Klefisch* Richard Klefisch

*Allen Kolons* Sharna Kohner

Joseph Koreen Kathi, Stuart, Jamie, Laura & Corey Rosenberg

*John L. Krieger* The Krieger Family

Sharon Lambing Larry & Kay Beckett Rita Boero James "Red" Boyle Tom & Mary Buhrkuhl Bonnie Cochrane Darlene Cole Concordia Lutheran Church Carol Dierker Fraternal Order of Eagles Aux #3781 Ann Gratza & Ervin J. Vlasak **Bill & Beverly Johnson** Karen Kilcullen & Dan Scheu Jo-Di Lambing Roger & Suzanne Louderman Jay & Gina Maben Gene & Jackie Martin James & Barbara Massie Wanda & Herman Merkel Missouri State Auxiliary Missouri State Auxiliary Officers Norma Jean Parker Russ & Emmy Rapp Helen M. Ruwwe & Family Dema Schatz Hester Tayloe Billie & Jack Tyler Doug & Diane Vaughn Patricia Webb

*Iris Levitt* Debbie & Karl Guyer

*Glenn Linke* Mike & Bernice Resnick

*Vance Lischer* The Lapp Family

*Nick J. Ludwig* Diane Ludwig

*Elizabeth Mack* Beverly & Jerry Silverman

*Tom A. Manglis* Anthony & Susan Cassimatis

**Brigida Manzo** Tom Gebken Greg & Francesca Grass Gene & Cindy Morgenthaler Amy & Joe Wolff

John Mayes Elizabeth Bail John & Colleen Hoercher Judy Kraske Mr. & Mrs. Eugene Munier Brian Randall Kent Schroeder Dave & Lisa Tiedemann

*Ed McPherson* CMW Equipment

Robert Miller Barbara Miller

*Evelyn Mitchell* Betty Tate

**Ramon Morganstern** Herb & Nancy Seidel Stan, Sally & Marci Zimmerman

*Fred Oertli, Jr.* Guarantee Electrical

*Dr. Sam Pagano* Stan & Angie Klearman

Don Pallo Roberta Hayman Jeffrey & Judy Pass Cheryl Perl

#### Angelo Panourgias

Louis & Catherine Anastasios Renée Becker Ron & Elaine Been Stephan & Melissa Bruce Jenell Brucker Ken & Terri Goodwin Kenneth & Sharon Goodwin Gus & Pat Hawkins Rich & Phyllis Hawkins The Irwin Family Brian & Dede Kelley Terry & Kathy Livaditis Jason Martin Pete & Sandy Martin Dr. Richard Schainker South Side Small Group Jane & Sandy Thal Stergios & Vedra Tsoulis Bob & Virginia Yale

Jim Peterson Jean Peterson

*Franklin Pinkston* Gail Gargac Denise & Andrew Jackson Tom & Bev Nance The Niemeyers Brandi Oller & Pilar Gallardo-Oller Jerry Volak David & Karen Warren

Rae Ann Powers Mr. & Mrs. Walter A. Kempter Pam & Ed Ponder Catherine M. Staten

*Al Rakers* Lyn & Bill Heaton

Mary Ann Rielly Thomas J Rielly

*Thomas Rosenburg* Neal & Lynn Grannemann

*Elfrieda Roth-Roffy* Paul Roth-Roffy

*Charles Ruscha* David Probstfield

*Goldie Satz* Bill & Terri Taylor

*Leo Schade* Kathleen Stones Sharon Wein

Jackie Schmidt Larry Schmidt

Paul Schmittling Mary Corvey Mike & Gail Glover Kari Hercules Susan & John Jasiewicz Sandy & Chris Knee Michael & Pam Reitmeyer Ray Schmittling & Families Judith Shoemaker Charles & Debra Thacker Kris Westhoff

*Selma Schumitsky* Roberta Hayman

*Elizabeth Schweizer* Gail & Larry Glenn

Jannette Schweppe Jerome & Cynthia Schonhoff

Ely Shrauner Bill & Roberta Abraham Katharine Abraham Sarah Abraham George & Abir Bazlamit Claude Bernard Elizabeth & William Caspari James & Carlee Caspari Matthew Caspari Deb & Jeff Clinebell Betty & Jim Dowd Matthew & Amy Dowd Michael & Jessica Friedlander Pat Gibbons Mr. Edward Greenberg Gary & Carol Hamilton Annaliesa & Wayne Hanebrink Margaret & Martin Israel Wilhelm Neuefeind Ruby E. Quarterman John & Fay Scandrett Barbara Shrauner James Shrauner Jay & Cynthia Shrauner Penelope Shrauner

*Raymond Siebert* Fred Jones

*John Skurat* Frank & Marilyn Schoeck

*Paul L. Slepski* Ted & Audrey Sanders Joan & Thomas Thompson

*Charles Standley* Diane & Dick Stonecipher

Donald Symank Bob & Pat Dillman Frank and Vanda Dillman Morris & Joyce Huelskoetter William & Jan Lauber

*Charles "Bud" Teeter* Allstates WorldCargo Family Ron & Lisa Ameln Don Hagemeier & Clara Veal Kenneth Mueller Gwynne Seigel Leslie Wilson

*Hattie Thal* Renee & Gary Harrison

Michael Tomko Stuart & Kathi Rosenberg George Trakas, Jr. Ed & Robin Biermann Tim & Jeannie Hallemann Greg & Kerri Klein Kathy Mester David & Kathleen Sandknop Bruce & Caryn Sandweiss

*Gordon E. Wall* Marilyn Wall

Ruth Warhoover Charles & Mary DeLong

Vernon Wein Sandra Aye Donald & Patricia Berendt Carol Betlejewski George & Janice Brennan Mr. & Mrs. Ernesto Cabrera **Russell & Bonnie Farrah** Joyce A. Foster Jackie & Dennis Hinderliter Jim & Marjorie Leuthauser Raymond & Joann Orr Peggy Piekarski Dale & Norma Plank Dan & Lori Schmidt Jim & Kathy Schweigert Patrick Scott Kermit Shelley & Immacolata Bergman-Shelley W.B & Norma Shelley Dave & Jean Stegmann Bob & Rhonda Stuckey Dorothy Wennemann Tom & Ruth Wiley

*Norma Ziegenhorn* Don Ziegenhorn

*Theodore Zinselmeier* Jack Strosnider, Sr.

#### GENERAL GIFTS UP TO \$99

Albert Barnett Dr. & Mrs. J.E. Creed Dick & Nancy Chin

**Rich Distler** Ronald Dunham Col. Walter & Marjorie Evans Norman V. Giovannini Gary Jones George Kantis Edith Kapfensteiner Michael & Nancy Klein David Lansdown Hadassah & Sanford Lebman James & Mary Jane Lister William & Rozanne Mannen Naomichi & Yohko Masaki Glenn & Carol McDevitt **Richard Saffley** Kathleen Safford Charles & Leona Sarkisian David Wiese K.L. & Mary Young Richard & Margaret Zimmerman

#### GENERAL GIFTS \$100 - \$499

Bill & Nancy Anderson Robert Babione Ed & Rita Balk Herb & Marge Bilinsky **Bill Billings** Jean Cody Col. & Mrs. Robert Coulter David & Patsy Dalton **EMD** Millipore Bill & Erika Gerth Mr. & Mrs. Michael J. Honigfort Ladue Chapel Women's Association Christel Maassen John & Susan Rothenheber Cynthia E. Smalley Marilyn F. Wall Gene & Patricia Wittman

#### GENERAL GIFTS \$500 - \$999

James Holsinger Marjorie A. Prunty Mary Stein

#### **GENERAL GIFTS**

\$1,000 – \$4,999 Thomas H. Benton, Jr. Rotonda Foundation Rich & Cheryl Schumacher Southern Illinois Support Group

#### **GENERAL GIFTS**

\$5,000 – \$9,999 Lucy Bauman Marilyn Decker George Von Hoffmann Foundation

#### GENERAL GIFTS \$10,000 AND OVER Guarantee Electrical

#### THRIVENT CHOICE DOLLARS

Rilla Fisher-Pugh & Dennis Pugh Kevin Hunter Carolyn Long David Long Louise Mrstik Roger Peters Flora Sanders

# **Drug Expense Relief**

Kathy McVoy, Caregiver

hew! Into the coverage gap I went. How much for entacapone (generic for comtan)? Did you say, \$888, and the next time \$768? REALLY! Down the wicked medicine slide we went into the coverage gap. My husband, Ken, and I have had to contend with the mammoth costs of his PD drugs for a couple of years. Ken, who has had Parkinson's for 9 years now, takes entacapone 7 times a day. He takes other drugs as well, but this one is the greediest emptier of pockets of them all.

Since we fall into a middle class coverage gap, it has been difficult to find assistance in reducing the cost of medications. We knocked on several doors to figure out how to lessen the expense. If you do not have insurance or your income is less than \$30,000, you can qualify for help with the Prescription Partnership Association, www.pparx.org. I called the manufacturer of the drug, Novartis, but they don't offer assistance. A very helpful fellow caregiver sent me to check out the Canadian mail order pharmacy route, which can be a good choice for some as they do offer reduced costs. Unfortunately, they wouldn't make a big difference for us because of the large amount of the drug Ken takes. You can go to affordabledrugs.com to learn more about this program. So, finally I spoke with Debbie Guyer, Executive Director of the Greater St. Louis Chapter. She suggested contacting Stacey Barton, a Social Worker with the Movement Disorder Center. Stacey was the caring, competent companion who walked me through the website Medicare.gov. You can go to the site and list all the drugs you need and compare which drug plan is most cost effective. I had visited the site before, but I didn't trust my assessment. I grew up dialing a phone and talking with people. How do you ask a computer, "Are you sure?" So, if you are like me and would like a guide through the process, ask a family member or friend, someone who is comfortable with the tech territory.

Just when you thought you could relax with this fairly simple solution, "heads up!" Stacey reminded me to check my drug plan each year. Plans change year to year and may not always cover the same drugs or cover them at the same cost.

So, I say, "Yay for a community of caring companions!" There are rocks along the path, and there are helpers to manage the stumbling. Thank you!



## A Slam Dunk!

The Cassville R-IV School District high school girls' basketball team raised funds and awareness about Parkinson disease on February 9, 2015, at the annual home game against Monett High School. This year they raised \$500 in honor of Coach Chris Shore's father, Charles, who battles Parkinson disease every day. This represents the second contribution made as a result of this game; the first, which raised \$448, occurred in 2013. We hope the community continues this tradition when Monett visits Cassville every other year.

# We Support Rekinsonis Alvarenss

### **Got Pizza?**

While raising awareness about Parkinson disease every Thursday during this past April, members of the Greater St. Louis APDA could dine in or carry out from all St. Louis locations of California Pizza Kitchen (CPK). CPK contributed a percentage back as a fundraiser for the Greater St. Louis APDA which resulted in receipt of \$548.55 for our cause! Thank you for your support again this year.

### **Bike-Swim-Run Triathlon**

The Chawla family raised \$1,300 this past April and May by participating in a bike/swim/run triathlon among their family and friends to honor the memory of loved one, Mr. Tilak Chawla. They exceeded their goal by getting multi-generations of the family members involved in this worthy cause. What a lovely tribute to a gentleman who holds such special meaning for so many.

### **One-of-a Kind Bob Gibson Hall of Famer Painting Prints Available**

This unique painting of St. Louis Cardinals Hall of Famer Bob Gibson was painted by local artist Kyle D. Lucks and auctioned at the Jack Buck Memorial Golf Classic held in May, 2015. Kyle has offered to sell prints of the painting and donate all of the proceeds to the APDA Greater St. Louis Chapter. To purchase your print, visit Kyle's website at http://www.kylelucks.com/product/bob-gibson/.



## The Worst Advice for Family Caregivers: Parent Your Aging Parents

Howard Gleckman, author of the book, Caring for Our Aging Parents.



n the always-complex, often-painful world of family caregiving, there is no worse advice than this: When your parents need help, you must reverse roles and become their parents.

Here is the reality: If you are the adult child of an aging parent, you will always be their child, and they will always be your parent. They may need your help with the most intimate personal care. But you will never become their parent.

I saw this all the time when I was researching my book, *Caring for Our Parents*. I had the opportunity to spend as long as two years with people who needed assistance and their family caregivers. I saw heartwarming successes and sad failures. Often the difference was the ability of adult children to understand their roles.

Courtland Milloy, in his column for the *Washington Post*t offered this guidance: "Some elder-care experts say that when aging parents stop acting in their best interest, the grown children must reverse roles and simply make them do the right thing." As he learned, this advice is so wrong on so many levels.

To start, what is the "right thing"? Who are you to decide what is right? As a matter of law and, I believe, ethics and morality, each of us gets to decide the "right thing" for our own life, as long as we are cognitively able and our choice does not harm others.

A wise man once said it like this: "When I was 22, I did some things my parents thought were remarkably stupid. But I was an adult and they were my choices. Now, my parents may be doing some things that I think are remarkably stupid. But they have the same right to make mistakes as I did."

Put yourself in the position of an aging parent. As you become physically frail and cognitively limited, you lose control of your life. All those day-to-day decisions that healthy people take for granted—when to go to the movies, when to eat, when to walk across the room and even when to go to the bathroom—are increasingly shared with others. It can be embarrassing and demeaning.

And it is why a big part of frail old age is about maintaining independence and respect.

Now comes your child. He may be 50 years old, but he is still your child. And he is saying: "Mom, you've got to go to the doctor," "You've got to stop driving," "You've got to move to assisted living." He may have just parachuted into town for a few days. He seems rushed and impatient. And you, who on some level still view your son as the 18-year-old who left home to go

to college, are resentful, embarrassed, and maybe even angry.

Needless to say, this is not a great environment in which to make decisions.

What's the alternative? As much as possible, share decision-making. As the adult child, never start any sentence with the words: "Mom, you've got to...." Instead, try, "What do you think we should do?" Help them choose. But work together as much as you can.

Of course, if a parent or other relative is emotionally or cognitively incapable of making decisions, you may have to step in. But that is much less common than many suppose.

To his credit, Milloy finally got it, despite starting out with that awful "reverse roles" advice.

Like the proverbial bad penny, this parenting your parents business keeps coming back. Years ago, when I was writing for *Business Week*, an editor suggested a consumer caregiving column. It would be called, you guessed it..."Parenting Your Parents." I told her I'd love to write the column but the name had to go. That was the last I heard about the idea.

*This article originally appeared in Forbes Magazine on September 4, 2013* 



## SEWING THE SEEDS OF OPTIMISM 20th Annual APDA Fashion Show, Luncheon and Auction

e're excited to bring you another delightful afternoon of fashion, delicious food and gifts from a silent auction filled with tastes of our town restaurant gift cards/ certificates and one-of-a-kind items. Proceeds from this event will be used to support APDA's dual mission – *to ease the burden and find the cure* by expanding patient programs and services to improve quality of life for individuals and family members and funding promising Parkinson research, which seeks to further identify causes and ultimately find a cure for Parkinson disease.

#### Invite your family, friends and neighbors!

We are thrilled to have **Kelly Jackson**, Anchor KSDK-TV and KTRS-Radio, and creator of Aarff.com and Jennifer Blome, Director of Humane Education, APD Missouri, and former Anchor of KSDK-TV morning newscast, *Today in St. Louis*, as our Masters of Ceremonies and to present fall fashions from some of St. Louis's finest boutiques including Mister Guy Clothiers (Men's and Women's fashions), Distinctions (formalwear), Vie, and Paperdolls.

Doors open for the silent auction and wine reception at 11:00 a.m., the luncheon will begin at 11:45 a.m., and the fashion show starts at 1:00 p.m. on **October 12, 2015**, at the Sheraton Westport Chalet. The cost will be \$70 per guest.

**How can you help?** Please consider becoming a *sponsor*. As a sponsor, you or your business will receive prominent placement in our program and on signage at the event, plus special seating at the fashion show. In addition, your name will be featured in the November **LiNK** newsletter distributed to over 9,500 homes and businesses across Missouri and Illinois. Sponsorships begin at \$500 with many levels to appeal to any supporter.

For more information about the fashion show and sponsorships, visit our website at **www.stlapda.org** or call the APDA office at **314-362-3299**. If you haven't received an invitation in the past and would like to receive one this year, please send an email to **malmengor@apdaparkinson.org** or give us a call. We'll gladly include you on our guest list! We hope you, your family and friends will join us to make this year's event another "fashionable" success!

Managing Constipation in Parkinson Disease continued from page 2

**Fiber must have fluids** Next, consider the need of fluid. The fiber particles you eat require water in order to swell up and keep the stool soft. Aim for at least six, 8 ounce servings of fluids each day, about half of which, ideally, would be plain water. Coffee and tea count, but the caffeine also causes some water loss. When taking medications, take them with an 8 ounce glass of water, rather than just the sip needed to swallow a pill. Other sources of water include soups, juices, smoothies, and a bowl of chopped mixed fruit (fruits and vegetables are naturally high in water content).

**Probiotics for gut health** Last, but just as important, consider the use of probiotics to maintain colon health. Although you can purchase gelcaps containing various probiotics, a much less expensive way is to eat fermented foods frequently- sauerkraut and kimchee are examples of fermented foods. Alternatively, make your own kefir. Kefir grains are small particles containing a wide variety of both bacteria and yeasts. When placed in milk, coconut milk, or sweetened water, the kefir grains consume the sugars, producing a fluid rich in microorganisms that are needed by the colon. For information and directions on making different kinds of kefir, visit the following websites:

http://www.culturesforhealth.com/how-to-activate-dehydrated-milk-kefir-grains-video

http://www.wikihowcom/Make-Kefir

#### http://www.waterkefir.org

A recent study showed that people with PD have an imbalance of microorganisms in the gut. These friendly organisms can also be depleted by use of antibiotics or a diet deficient in the prebiotic substances they rely on for food. Prebiotics are certain types of fiber-fructo-oligosaccharides and inulins - which are not digested by humans but pass into the colon and are used as food by these friendly organisms. Eating a variety of high-fiber foods will ensure that your colon receives prebiotics for the probiotics to consume.

For more information on this and many topics, visit www. nutritionucanlivewith.com.

This article appeared in the NWPF publication on May 8, 2015, and is reprinted with permission of NWPF and the author.



Sponsored by the American Parkinson Disease Association, Greater St. Louis Chapter

# **Missouri Support Group Calendar**

Our support groups meet once a month or as noted. Support group day and time may change periodically. For current updates on support groups and exercise classes, check our website, **www.stlapda.org**, or call the APDA Information & Referral Center or the facilitator. Information that has changed since the last **LiNK** appears in **bold**.

CITY	COUNTY	MEETING SITE	DAY OF MEETING	TIME	LEADER(S)	PHONE
Ballwin	St. Louis	Meramec Bluffs Care Center 40 Meramec Trails Dr., Activities Rm.	4th Tuesday	2:00 PM	Gayle Truesdell	636.923.2364
Cape Girardeau	Cape Girardeau	Cape Girardeau Public Library 711 N Clark Street, Oscar Hirsch Room	3rd Monday	6:00 PM	Desma Reno, RN, MSN	573.651.2939
Chesterfield	St. Louis	APDA Community Resource Center 1415 Elbridge Payne, Suite 150	1st Tuesday	10:30 AM	Mary Buck	636.532.6504
Chesterfield	St. Louis	For Caregivers Only APDA Community Resource Center 1415 Elbridge Payne, Suite 150	2nd Monday	10:30 AM	Dee Jay Hubbard, PhD	314.362.3299
Columbia	Boone	Lenoir Community Center 1 Hourigan Drive	1st Thursday	4:00 PM	Patsy & David Dalton	573.356.6036 573.434.4569
Creve Coeur	St. Louis	Pre/Post-DBS Group Missouri Baptist Medical Center 3015 N. Ballas, Main Parking Garage 4th fl. CLI Rm. 419	3rd Tuesday	6:30 PM	Joe Vernon	314.614.0182
Creve Coeur	St. Louis	Young Onset Living and Working with PD Missouri Baptist Medical Center 3015 N. Ballas, Main Parking Garage 4th fl., CLI Rm. 419	3rd Tuesday	6:30 PM	Doug Schroeder	314.306.4516
Festus/ Crystal City	Jefferson	Disability Resource Association 130 Brandon Wallace Way	3rd Tuesday	1:00 PM	Penny Roth Sara Dee	636.931.7696 x129
Florissant	St. Louis	Garden Villas North 4505 Parker Rd.	4th Thursday	11:00 AM	Nancy Robb	314.869.5296
Jefferson City	Cole	Capital Regional Medical Center SW Campus, Cafeteria	3rd Wednesday	3:00 PM	Jennifer Urich, PT David Urich	573.632.5440 573.796.2395
Joplin	Jasper	Byers United Methodist Church 1730 S. Byers, Gymnasium	Every Monday	3:00 PM	Nancy Dunaway	417.623.5560
Kansas City	Jackson	VA Medical Center 4801 Linwood Blvd. Hall of Heroes Room	3rd Tuesday	11:00 AM	Jesus Torres Nikki C. Caraveo, RN, BSN, CNRN	816.861.4700 x56765
Kirkwood	St. Louis	Kirkwood United Methodist Church 201 W. Adams, Room 201	4th Tuesday	7:15 PM	Terri Hosto, MSW, LCSW	314.286.2418
Ladue	St. Louis	The Gatesworth 1 McKnight Place	2nd Wednesday	1:00 PM	Maureen Neusel, BSW	314.372.2369
Lake Ozark	Camden	Lake Ozark Christian Church 1560 Bagnell Dam Blvd.	3rd Thursday	Noon	Patsy & David Dalton	573.356.6036 573.434.4569
Poplar Bluff	Butler	Poplar Bluff Regional Medical Center 3100 Oak Grove Rd. Ground Floor Education Room 3	2nd Monday	6:00 PM	Charles Hibler register with Beryl or Dana	573.785.6222 855.444.7276 573.776.9355
Rolla	Phelps	Phelps County Regional Medical Center, Pulaski Room, 1000 W. 10th St.	4th Thursday	2:30 PM	Sarah Robinson	573.201.7300
South St. Louis	St. Louis	Garden Villas South 13457 Tesson Ferry Rd.	2nd Wednesday	10:00 AM	Jack Strosnider	314.846.5919
Springfield	Greene	Mercy Hospital 1235 E. Cherokee	2nd Thursday	2:00 PM	Valerie Givens, RN	417.820.3157

continued from previous page

# **Missouri Support Group Calendar**

CITY	COUNTY	MEETING SITE	DAY OF MEETING	TIME	LEADER(S)	PHONE
St. Peters	St. Charles	Spencer Road Library 427 Spencer Rd., Room 259	1st Tuesday	1:00 PM	Sherrie Rieves Ann Ritter, RN	636.926.3722
Ste. Genevieve	Ste. Genevieve	Ste. Genevieve County Mem. Hospital Education Conf. Room, Hwy. 61 & 32	2nd Wednesday	10:00 AM	Jean Griffard, RN	573.543.2162
Trenton	Grundy	Royal Inn 1410 E. 9th Street	1st Thursday	10:00 AM	Novy & Mary Ellen Foland Gloria Koon	660.357.2283 660.485.6558
Washington	Franklin	Washington Public Library 410 Lafayette Avenue	2nd Monday	6:30 PM	Carol Weber	314.713.4820
Webster Groves	St. Louis	Bethesda Institute 8175 Big Bend Blvd., Suite 210	Last Friday	10:30 AM	Laurel Willis, BSW	314.373.7036
Webster Groves	St. Louis	Laclede Groves 723 S. Laclede Station Rd.	3rd Wednesday	3:00 PM	Dina Spies	314.446.2594



# **Illinois Support Group Calendar**

Our support groups meet once a month or as noted. Support group day and time may change periodically. For current updates on support groups and exercise classes, check our website, **www.stlapda.org**, or call the APDA Information & Referral Center or the facilitator. Information that has changed since the last **LiNK** appears in **bold**.

CITY	COUNTY	MEETING SITE	DAY OF MEETING	TIME	LEADER(S)	PHONE
Alton	Madison	Senior Services Plus 2603 N. Rodgers Ave.	2nd Tuesday	9:30 AM	Kim Campbell	618.465.3298 x146
Belleville	St. Clair	Southwestern Illinois College (PSOP) 201 N. Church St., Rm 106	2nd Monday	1:30 PM	Jodi Gardner	618.234.4410 x7031
Carbondale	Jackson	Southern IL Healthcare Headquarters University Mall	1st Wednesday	1:00 PM	Bill Hamilton, M.D.	618.549.7507
Centralia	Washington	Heritage Woods of Centralia 2049 E. McCord St.	2nd Wednesday	2:00 PM	Dennis Krupp Betty Evans Helena Quaid	618.545.6597 618.533.0224 618.493.6064
Champaign	Champaign	Savoy United Methodist Church 3002 W. Old Church Road	Every Monday	10:00 AM	Charles Rohn Chuck Arbuckle	217.549.6167 217.586.3100
Decatur	Macon	Westminster Presbyterian Church 1360 West Main Street	3rd Thursday	1:30 PM	John Kileen	217.620.8702
Glen Carbon	Madison	The Senior Community Center 157 N. Main St.	3rd Wednesday	10:30 AM	Nancy Goodson Rich Rogier	618.670.7707 618.288.3297
Greenville	Bond	Bond County Sr. Center 1001 E. Harris Ave.	4th Monday	10:30 AM	Anna Oestreich	618.664.1465
Greenville	Bond	Bond County Sr. Center Baumberger Comm. Rm. CAREGIVERS ONLY	4th Friday	1:00 PM	Anna Oestreich	618.664.1465
Jacksonville	Morgan	Passavant Area Hospital 1600 W. Walnut–Meeting Room 2	1st Wednesday March-December	6:00 PM	Karen Ladd	217.377.4973
Mattoon	Coles	First General Baptist Church 708 S. 9th St.	Last Tuesday	1:30 PM	Roy and Kay Johnson	217.268.4428
McLeansboro	Hamilton	Heritage Woods – Fox Meadows 605 S. Marshall Ave., Dining Room	1st Wednesday	1:00 PM	Paula K. Mason	618.643.3868
Springfield	Sangamon	St. John's Rehab. @ Fit Club South 3631 S. 6th. Street #C	3rd Sunday Odd numbered months: 1,3,5,7,9,11	2:00 PM	Kelly Neumann, PT	217.483.4300



## **Exercise Classes**

The APDA now offers 17 exercise classes that meet weekly. Exercise is essential to managing Parkinson symptoms and slowing the progression of the disease. Our patient services funding comes from donations and is limited, so we encourage those who wish to attend multiple classes to make a \$5 per week donation. This minimal donation helps us defray the cost of the classes which run around \$10 per person to cover the instructors' salaries, room rentals, and equipment. This donation request is on an honor system, and we don't turn anyone away from attending as many classes as they choose. To make a donation for exercise classes, use the blue envelope in your newsletter and note that it is for exercise class. Many people choose to pay quarterly to reduce the number of checks they write each month. Any amount you can contribute is used exclusively for our patient services to keep these programs free or at little cost to our patients.

Our exercise classes meet once a week or otherwise as noted. Information that has changed since the last LiNK appears in **bold**. Attend one class per week at no charge, or for \$20/month attend as many classes as you want. No RSVPs are required. Check our website, www.stlapda.org, or call to find out any changes since publication.

CITY	COUNTY	MEETING SITE	DAY OF MEETING	TIME	LEADER(S)	PHONE
Clayton	St. Louis	The Center of Clayton 50 Gay Ave., Mind/Body Room	Wednesday & Friday	2:00 PM	Mike Scheller, PTA	314.289.4202
Chesterfield	St. Louis	St. Luke's Deslodge Outpatient Center 121 St. Luke's Center Drive Conference Rooms 1 & 2	Monday	10:00 AM	Sarah Farnell, OT	314.205.6934
Chesterfield	St. Louis	Friendship Village 15201 Olive Blvd. Friendship Hall-Door #5	Tuesday	1:30 PM	Jessica Andrews	636.733.0180 x7719
Chesterfield	St. Louis	Parkinson Resource Center 1415 Elbridge Payne, Ste. 150	Monday	1:30 PM	Becky Miller, DPT	314-362-3299
Chesterfield	St. Louis	Tai Chi APDA Community Resource Center 1415 Elbridge Payne, Suite 150	Wednesday or Friday	10:00 AM 11:30 AM	Craig Miller	314.362.3299
Chesterfield	St. Louis	Yoga Maryville University, Walker Hall Reservations Required	Wednesday	6:30 PM	Pradip Ghosh, PT, PhD	314.362.3299
Creve Coeur	St. Louis	Aquatic Exercise Rainbow Village 1240 Dautel Lane	Summer Session July 6-Sept. 11	1:00 PM Tuesdays	Brenda Neumann	636.896.0999 x21
Florissant	St. Louis	Garden Villas North 4505 Parker Rd.	Tuesday	10:00 AM	Bobby Lautenschleger, PTA	314.355.6100
Joplin	Jasper	United Methodist Church 1730 Byers Ave.	Monday	2:15 PM	Nancy Dunaway	417.623.5560
Kirkwood	St. Louis	RehabCare 439 S. Kirkwood Rd., Ste.200 Park in rear	Thursday	1:00 PM	Brandon Takacs	618.971.5477
Ladue	St. Louis	Tremble Clefs Singing Salem United Methodist 1200 S. Lindbergh Blvd. Lower Level Choir Room	Saturday	1:30 PM	Linda McNair	314.362.3299
South St. Louis County	St. Louis	Garden Villas South 13457 Tesson Ferry Rd.	Monday	11:30 AM	Mike Scheller, PTA	314.289.4202
St. Peters	St. Charles	Barnes-Jewish St. Peters Hospital Healthwise Center, 6 Jungermann Circle	Tuesday	11:00 AM	Holly Evans, COTA	636.916.9650
St. Peters	St. Charles	Aquatic Exercise St. Charles YMCA 3900 Shady Springs Ln.	Summer Session July 6 – Sept. 11	1:45 PM Thursdays	Brenda Neumann	636.896.0999 x21
Lake Ozark	Camden	Lake Ozark Christian Church 1560 Bagnell Dam Blvd.	Monday	4:00 PM	Alice Hammel, RN	573.964.6534
Greenville, IL	Bond	Bond County Sr. Center 1001 E. Harris Ave.	Wednesday	10:30 AM	Anna Oestreich	618.664.1465



Help us manage our expenses by letting us know when you move, if you want to be removed from the mailing list, or if you'd rather receive an electronic version. Just call **314.362.3299** or email **guyerd@neuro.wustl.edu** to let us know! Thank you in advance for helping us spend our resources wisely!



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SAVE

THE DATE



#### **American Parkinson Disease Association**

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## AUGUST 15, 2015

**Hull of a Race** – participate in the 10th annual race to raise funds for Parkinson research, held in Hull, Illinois. More information can be found on their website, www.hullofarace.com. Both 5k and 10k race courses are certified. The race is the kickoff for the Hull picnic – featuring a fried chicken dinner that same night.

## OCTOBER 12, 2015

**20th Annual Sewing the Seeds of Optimism** auction, luncheon, and fashion show held at the Sheraton Westport Chalet. Tickets are sold on a first come, first serve basis. More information is available on our website, www.stlapda.org/services/fashion-show.



## OCTOBER 31, 2015

Partners in Parkinsons (PIP) invites you and your family to attend this event in Collinsville, IL. To learn more or to sign up, visit: It ps://www.partnersinparkinsons.org/apide/saintlouis. Partners arkinson's beins patients and caregivers gain knowledge and support



in Parkinson's helps patients and caregivers gain knowledge and support for navigating a Parkinson's diagnosis and the PD progression in order to optimize care at every stage of the disease. Whether you're new to Parkinson's or have been living with the disease for years, attend this free full day of interactiv

or have been living with the disease for years, attend this free full day of interactive panel discussions and breakout sessions learn about living with Parkinson disease, building the right care team (including when and how to seek specialist care), ask your own questions, and connect with Parkinson resources in your own community. Browse a resource fair to connect with leaders from your local medical and Parkinson's community (local clinicians and movement disorder specialists, allied care providers specializing in PD, research sites conducting local studies, and support and advocacy organizations). Partners in Parkinson's has been developed by The Michael J. Fox Foundation for Parkinson's Research and AbbVie.

## **NOVEMBER 15, 2015**

Parkinson Educational Program (PEP) featuring Dr. Joel Perlmutter, **Debunking Myths About PD**, will be held at Congregation Shaare Emeth, 11645 Ladue Rd. in Creve Coeur starting at 2:00 p.m.